

## The Issue In Depth

### **We Are Failing To Prevent Needless Suffering**

Everyday, children are born with potentially life threatening allergies and related diseases which prohibit them from consuming the foods and formulas required for proper life sustaining nutrition. These children, approximately 0.1% of the total U.S. infant and children's population, are left with few options for sustenance. For many, the best option, a diet of amino acid-based elemental formulas that provides the nutrition required for natural growth and development is unavailable. And for others, the simplest of remedies, the usage of liquid formulas to maintain proper nutrition, has become extremely invasive and very expensive.

Most children typically encounter one or more of the following three **FIXABLE** problems in their pursuit of a healthy life;

- Some children are unable to benefit from life saving amino acid-based elemental foods because they are simply born into a family that can not afford the high cost of amino acid-based elemental formulas;
- In other cases, in order to receive proper nutrition, children and infants are often forced to undergo unnecessary invasive procedures, such as an operation to insert a feeding a tube directly into a child's stomach, because health insurers refuse to cover less invasive feeding methods;
- Many children are put through a battery of tests and clinical visits costing thousands of dollars and causing parental mental anguish before a diagnosis is determined.

The problems above are easily fixable and should not be impediments to life sustaining nutrition.

### **Fixing The "Baby Gap"**

Families over the poverty level and earning a 'living wage' are at a chronic disadvantage in gaining affordable access to adequate health care support. Currently, the Women, Infants, and Children's Program (WIC) and the state Medicaid program cover these medically necessary amino acid-based elemental formulas for infants and children suffering from food allergies and disease. However, most state private insurance providers do not include coverage, creating a "baby gap" of families with private insurance, but without reimbursement assistance.

### **A Contradiction In Logic**

A child living with multiple allergies and digestive problems can sometimes only maintain proper life sustaining nutrition with elemental formulas. There are two ways to feed a child amino acid-based elemental formulas:

- Orally by using a bottle or cup, or:
- Enterally, through a feeding tube inserted into the child's stomach during an operation.

In most instances insurers will cover the cost of the surgical procedure to insert the tube, and the hospital admission (inpatient or outpatient), but they will not cover the cost of the same formula if it is delivered orally through a bottle or cup. This is a contradiction in logic. Oral feeding is less invasive, less expensive, and much easier on the child and the parents than inserting a feeding tube into an infant's stomach. We should be making a child's first moments as easy as possible; we should not have health care policies that require a child to undergo a clinical procedure in order to receive necessary life sustaining nutrition. Insurers should be required to cover amino acid based elemental formulas regardless of delivery method as long as they are required and being administered at the direction of a health care professional.

### **Working Backwards – Elemental Formulas As A Testing Tool**

Parents of children with severe allergies or diseases are left looking for an answer to the question of "Why is my child sick?" Their search for answers often results in multiple visits to the emergency room for the family followed by many visits to a pediatrician, allergist or gastrointestinal specialist. During these visits a variety of invasive and costly tests can be performed multiple times and many yield inconclusive or flawed results. Ninety percent of all food allergies are caused by dairy, eggs, fish, shellfish, peanuts, tree nuts, wheat and soybeans; very few children have multiple food allergies or gastrointestinal diseases. Yet, children with even the most basic of allergies are put through the same invasive tests as a child with severe multiple conditions. If amino acid-based elemental formulas were covered by insurers, just like prescription medications, health care professionals could direct infants and children to a diet of only amino acid-based elemental formulas and slowly reintroduce "normal" foods back into the child's diet; in many cases, such a process would avoid invasive tests and procedures and allow a doctor to reach the same diagnosis. This process of "reintroduction" would be more cost effective for the insurance company and less harmful to the patient and family. Insurers should be required to cover amino acid-based elemental formulas regardless of delivery method and for testing purposes as long as they are being administered at the direction of a health care professional.

### **The Cost To Insurers Is Virtually Nothing**

During a hearing, Ohio State Senator Gene Krebs stated that formula legislation “would raise premiums 1.6 pennies a year for the average family” because so few are actually affected. Amino acid-based elemental formulas cost the median family approximately a tenth of their annual income. An increase of this size is a small price to pay for a child’s well being and for family financial relief.

No parent should be forced into making their child’s health a financial decision and no child should be forced to undergo several diagnostic tests and procedures in order to get proper nutrition when a less invasive process and delivery method exists. Children who are allergic to multiple foods or basic infant formulas that are forced to continue eating typical foods experience persistent diarrhea, bloody stools, poor weight gain, persistent vomiting, severe skin rashes, respiratory distress, extreme fussiness, and an overall failure to thrive. In some children, the reaction to the offending food/allergen may be so severe that the child can suffer shock, breathing difficulty, convulsions and possibly death. Today, parents of these children are forced to trade-off their child’s health with significant financial hardship when private insurance refuses to provide assistance for life-sustaining nutrition. By requiring insurers to cover amino acid-based elemental formulas, regardless of delivery method and for any medically necessary conditions as determined by the child’s health care provider, we are making a child’s health the first priority and removing harmful contradictions of reimbursement coverage.

### **Other States With Common Sense Health Care Policies**

Six states, in one form or another, cover amino acid-based elemental formulas. These states have recognized the importance of a healthy child’s existence while also recognizing that insurance premiums will not skyrocket. In fact, amino acid-based elemental formulas can do just the opposite and limit long-term health expenses. By enabling a child to grow and thrive normally, the cost of future tests and treatments due to the retardation of normal growth and development associated with improper nutrition is dramatically reduced.

States with legislative mandates for amino acid-based formula coverage are: Arizona, Connecticut, Illinois, Massachusetts, Minnesota, New Hampshire, New Jersey and New York.

### **What Is An Amino Acid-Based Elemental Formula?**

Amino acid-based elemental formulas are made from individual (single) non-allergenic amino acids unlike regular dairy (milk or soy based) formulas and foods that contain many complete proteins. Amino acid-based elemental formulas are made of proteins broken down to their “elemental level” so that they can be easily absorbed and digested. In many cases, amino acid-based elemental formulas are the only thing an infant or child can properly digest and tolerate due to various allergies or gastrointestinal conditions.

### **What Is The Solution To This Crisis?**

The lack of private insurance reimbursement assistance for amino acid-based elemental formulas and medically necessary foods for the 5-8% of children who are allergic to certain foods is the cause of the medical crisis. Providing these formulas and medical food is the solution. In most states today, children face deteriorating health often resulting in hospitalization, because these products are not covered by insurance, although Medicaid and WIC do cover for those qualifying for those programs. Amino acid-based elemental formulas are not new and their efficacy has long been proven. The fact is that within two weeks of being placed on an amino acid-based elemental formula or medical food, infants and children experience a world of difference. Hives and rashes clear up, diarrhea disappears, and all the child's symptoms begin to clear up. After a few months, the children will have returned to normal weight, continue normal growth, and become normal, healthy children. Amino acid-based elemental formulas work wonders when it comes to helping children get back on a track toward a healthy existence.

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### **Children's Milk Allergy and Gastrointestinal Coalition**

Children's Milk Allergy and Gastrointestinal Coalition (MAGIC) is composed of parents, advocacy organizations, health institutions and like minded groups to promote healthcare coverage and reimbursement of elemental formulas for children who are unable to consume a natural, life-sustaining diet due to various allergies or diseases.